

Report to Congress on Autism

Prepared by the National Institute of Mental Health
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Report to Congress on Autism: Children's Health Act of 2000 Fiscal Year 2005

Executive Summary

This is the annual Report to Congress on Autism required by Public Law 106-310, the Children's Health Act of 2000. The report provides an overview of activities conducted by the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) concerning the implementation of each section of the Act. In 2005, the NIH, CDC, and HRSA continued to make substantial progress in the research, diagnosis, and treatment of autism, in addition to enhancing education and public outreach activities. NIH continues to support the Studies to Advance Autism Research and Treatment (STAART) Network, which is composed of eight centers. NIH also funds the Centers for Children's Environmental Health and Disease Prevention and has expanded activities of the Collaborative Programs of Excellence in Autism. The CDC oversees the National Autism and Pervasive Developmental Disabilities Surveillance Program, the Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology, and the autism awareness campaign—*Learn the Signs. Act Early.* HRSA continues to support two long-standing programs for the training of health professionals: the Leadership Education and Neurodevelopmental Disabilities Program and the Developmental-Behavioral Pediatrics Program. Further, HRSA has continued to fund the development of comprehensive, community-based service systems for children with autism and their families. In addition to the large programs and centers supported by the NIH, CDC, and HRSA, these agencies engage in a number of collaborative efforts to collect, store, and disseminate information in order to enhance autism research, services, and outreach.

Introduction

Autism is a complex neurobiological disorder that causes extreme and pervasive impairment in thinking, feeling, language, and the ability to relate to others. Autism is part of a group of disorders called autism spectrum disorders (ASDs), also known as pervasive developmental disorders. ASDs range in severity, with autism being the most debilitating form while other disorders, such as Asperger syndrome, produce milder symptoms. Autism is usually first diagnosed in early childhood and persists throughout the lifetime of the individual. Autistic behaviors not only make life difficult for people with autism but also make life hard for their families, health care providers, and teachers. Families coping with this devastating disorder are searching for information about the causes, diagnosis, treatment, and prevention of autism. Presently, there are no fully effective means to prevent, treat, or cure the disorder. Early intervention is critical for affected children to gain maximum benefit from current therapies. Although the full cost to society is unknown, autism affects all racial, ethnic, and social groups and causes tremendous economic and social burden.

Purpose of the Report

Public Law 106-310, the Children's Health Act of 2000, was signed into law on October 17, 2000. Division A, Title I, of the Act authorizes the Secretary of Health and Human Services (HHS) to conduct certain activities relevant to autism and pervasive developmental disorders, as follows:

- Section 101: Expansion, Intensification, and Coordination of Activities of the National Institutes of Health with Respect to Research on Autism;
- Section 102: Developmental Disabilities Surveillance and Research Programs;
- Section 103: Information and Education;
- Section 104: Interagency Autism Coordinating Committee; and
- Section 105: Providing this report to Congress.

Descriptions of the requirements mandated by each Section are provided below:

Section 101 authorizes the Director of NIH, acting through the Director of the National Institute of Mental Health (NIMH), to expand autism research activities and to support the specific planning and establishment of no fewer than five Centers of Excellence in Autism Research. Each center should conduct basic and clinical research on the research topics of the causes, diagnosis, early detection, prevention, control, and treatment of autism. Collectively, the centers should conduct research in the fields of developmental neurobiology, genetics, and psychopharmacology. Support to the centers is not to exceed a period of 5 years, but support may be extended for one or more additional periods based on appropriate peer review. In order to facilitate research, Section 101 also authorizes a program through which samples of tissues and genetic material should be collected, preserved, and shared. Furthermore, the Director should provide a means through which the public may obtain information about existing and planned programs on autism at the NIH, and the Director should be able to receive comments from the public about these programs.

Section 102 authorizes the Secretary of HHS to act through the Director of the CDC to create a surveillance program for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities. This portion of the Act requires the establishment of three regional Centers of Excellence for the purpose of collecting and analyzing information on the number, incidence, correlates, and causes of autism and pervasive developmental disorders. The section also calls for establishing a clearinghouse for the collection and storage of data generated by the surveillance programs. The clearinghouse will facilitate the coordination of research and policy development relating to the epidemiology of autism.

Section 103 authorizes the Secretary to establish and implement a program to provide education and information to health professionals and the general public on autism, including advances in the diagnosis and treatment. Continuing education programs should be provided to scientists, physicians, and other health professionals who provide care for patients with autism.

Section 104 stipulates that the Secretary establishes a committee to be known as the Interagency Autism Coordinating Committee (IACC) to coordinate all efforts within HHS concerning autism. The Committee is to be composed of the Directors of the relevant NIH Institutes, the

CDC, and other agencies and officials that the Secretary determines to be appropriate. The Secretary also may appoint to the IACC parents or legal guardians of individuals with autism or pervasive developmental disorders, as well as representatives of other governmental agencies that serve children with autism, such as the Department of Education.

Section 105 requires the Secretary of HHS to submit an annual report to Congress "concerning the implementation of this title and the amendments made by this title." The following report summarizes the HHS activities in 2005 pertinent to each section of Division A, Title I, of the Children's Health Act of 2000.

Section 101—Expansion, Intensification, and Coordination of Activities of the National Institutes of Health with Respect to Research on Autism

a. Expansion, Intensification, and Coordination of NIH Activities

Six Institutes are members of an internal NIH coordinating group that is separate from the IACC created in P.L. 106-310. This group, the NIH Autism Coordinating Committee (NIH/ACC), is composed of the NIMH, the National Institute of Child Health and Human Development (NICHD), the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Environmental Health Sciences (NIEHS), and the National Institute of Nursing Research (NINR). In addition, a staff representative from the National Institute of Allergy and Infectious Diseases (NIAID) participates in NIH/ACC meetings.

The NIH/ACC coordinates autism research activities funded and conducted by the various NIH Institutes. Representatives from the NIH/ACC attend meetings of the IACC and act as liaisons between the two committees, ensuring that NIH addresses IACC concerns and issues. As co-chairs of the NIH/ACC, the Director of NIMH and the Director of NICHD oversee those activities. The Secretary of HHS delegated to NIH the authority to convene the IACC, which NIH then delegated to NIMH. Therefore, the NIMH Director serves as chairperson of the IACC.

Over the past few years, NIH has considerably expanded its autism research portfolio and enhanced its coordination of autism research. NIH support of autism research grew from \$22 million in FY 1997 to approximately \$102 million in FY 2005. The Institute members of the NIH/ACC have made a clear commitment to the broad intensification of autism research efforts called for in the Act. These efforts include a large number of grants, contracts, and intramural research programs distributed across the NIH.

In FY 2005, NIH autism research activities included the following:

The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism

Established in 1997, the NICHD/NIDCD Network on the Neurobiology and Genetics of Autism currently consists of nine Collaborative Programs of Excellence in Autism (CPEAs). Investigators within the CPEAs have characterized more than 2,200 families with autism, the world's largest group of well-diagnosed individuals with autism for whom both genotypic and extensive phenotypic data are available for researchers to study. This network conducts basic and clinical research on the possible genetic, immunological, neurobiological, and environmental causes of autism. The network also investigates the developmental course of autism and how the development and function of brain structures relate to autism. These undertakings require that each CPEA implement a cohesive, site-specific, multidisciplinary research program on the causes, brain substrates, functional characteristics, and clinical development of autism spectrum disorders. In addition, each site must participate in a trans-network collaborative study for which no single site has sufficient expertise and/or subject population.

The major CPEA sites remain Boston University, Boston; University of California, Los Angeles; University of California, Davis; University of Washington, Seattle; University of Pittsburgh, Pittsburgh; University of Rochester, Rochester; University of Utah, Salt Lake City; University of Texas, Houston; and Yale University, New Haven. Over the last 8 years, individual CPEA sites completed genetic studies of autism; undertook studies of early brain function and abnormal brain anatomy in children with autism; developed methods for early recognition and diagnosis of autism and devised a new method for assessing social functioning in individuals with autism; furthered the characterization of the phenotype of autism spectrum disorders; conducted intervention studies using randomized clinical trials; and described environmental factors associated with improved development in children with autism spectrum disorders. In 2002, NIH renewed the funding of the CPEA sites for an additional 5 years. NICHD and NIDCD plan to allocate \$60 million during this time period to sustain and enhance the CPEAs.

Because of the large number of autistic individuals enrolled in the CPEA research programs, the network is able to undertake studies that would be difficult or impossible to conduct at a single research site. Completed network projects evaluated the effectiveness of the hormone, secretin, in the treatment of autism; the candidate autism genes, *HOXA* and *Reelin*; executive functions (i.e., planning, reasoning, impulse control) in autism; language functions in autism; and a genetic linkage study of autism in siblings. During the past year, CPEA investigators completed the network project on the relationship between head circumference and autism, involving 338 participants with autism spectrum disorder, 147 parents, and 149 siblings. These investigators will soon submit the resulting manuscript for publication. Other CPEA investigators completed a network project on the cognitive profiles of preschool aged children with autism. The manuscript describing this study is currently under review. Finally, for a third and ongoing network project, investigators are studying gender differences in adaptive skills as a function of age or developmental level.

NIEHS/EPA Children's Centers

NIEHS, in partnership with EPA, supports autism research through a national network of Centers for Children's Environmental Health and Disease Prevention Research (NIEHS/EPA Children's Centers). Two of the centers, located at the University of California at Davis and the University of Medicine and Dentistry of New Jersey (UMDNJ; Piscataway), focus on identifying and understanding environmental influences in autism. The UC-Davis center is conducting the first large epidemiologic case-control study of children with autism. Investigators have begun to analyze data collected from young children with autism, revealing important findings on the relationship between adaptive development and sleep patterns, and between head circumference and other growth parameters. In addition, investigators at this center are establishing models of human social behavior in mice and nonhuman primates. These methods are being applied in animal studies to identify genetic factors that may interact with environmental exposures to increase risk of social behavior deficits.

The NIEHS/EPA Children's Center at the UMDNJ has continued to enroll children in a unique study designed to comprehensively evaluate the autistic child's personal, residential, and community environments. Several basic science projects conducted at this center are using cellular and animal models to explore the interaction between model neurotoxicants such as lead and methyl mercury, with aspects of early brain development and with the emergence of specific behavior patterns. A new focus of these projects is to identify treatments that may prevent or ameliorate any toxicant-induced damage that is observed.

A new round of competition for the NIEHS/EPA Children's Centers was announced in August 2005. Applications will be accepted from existing or new centers that propose research to explore environmental etiologies of childhood disorders affecting the nervous and/or endocrine systems, and autism is one of several disorders of interest. Applicants are required to incorporate community-based participatory research and translational activities into their centers. These activities are aimed at strengthening partnerships between scientists and community groups in ways that enrich the research process, from study planning to evaluation and dissemination of findings. Five-year awards for the NIEHS/EPA Centers will be made in 2006.

b. Centers of Excellence

The STAART Network continues to make considerable progress in autism research. The STAART Network was born out of the Children's Health Act of 2000, which called for NIH to establish at least five Centers of Excellence in Autism Research. In response to this charge, NIH implemented a program that meets and exceeds the specifications of the Act regarding the organization, scientific goals, and other characteristics of the program. The goal was to establish several research centers that would unite expertise, infrastructure, and resources focused on major questions about autism. In 2002, two centers were funded at the University of North Carolina (Chapel Hill) and Yale University (New Haven). In 2003, six additional centers were funded by five participating NIH Institutes (NIMH, NINDS, NICHD, NIDCD, and NIEHS). The six centers are located at the University of Washington, Seattle; the University of California, Los Angeles; Boston University, Boston; the University of Rochester, Rochester; the Kennedy

Krieger Institute, Baltimore; and Mt. Sinai Medical School, New York. In 2005, NIH spent approximately \$13 million in total funds to support the STAART Network. NIH funding supports the eight centers, the data coordination center, and collaborative projects among the centers. The Steering Committee of the STAART Network determines the exact nature of the cooperative studies.

The STAART centers are contributing to the understanding of autism by investigating areas such as early detection through behavioral and/or biological markers, efficacy of early interventions, early course of core features, biological bases of the core deficits, efficacy of treatments for social deficits, efficacy trials for pharmacotherapy, genotype and phenotype of response to treatment, and identification of susceptibility genes. As a requirement of participation in the STAART Network, each center has at least one treatment project. A collaborative, multi-site psychopharmacology clinical trial was launched in 2004. A feasibility study for a second collaborative psychopharmacology trial is currently under way.

The STAART centers interact with the CPEA Network through a number of mechanisms, including a common imaging subcommittee and a combined common measures/data sharing subcommittee. In 2003, the NIH established a data-coordinating center (DCC), designed specifically to expedite and to maximize the analysis of data generated by both the CPEA research projects and the STAART Network. This DCC provides administrative support, project management support, and data management support, as well as customized system applications for both the CPEA and the STAART centers. The major focus of the DCC during the past year was the formation of a warehouse for collecting data on common measures for both networks. The DCC also continues to provide project and data management support for the pharmacologic, multi-site randomized control trials of the STAART Network. During the past year, scientific advisors requested that the CPEA and STAART Networks create a cross-network public Web site to provide an additional venue for research dissemination. The DCC is currently finalizing the Web site, which will be released during the joint CPEA and STAART annual meeting in November 2005.

The STAART and CPEA centers are discussing potential collaborations to combine data from their diverse samples in order to increase the ability to detect deviations in brain development in relationship to clinical features (e.g., gender, age, behavioral symptoms). For example, CPEA investigators initiated a collaborative project between the CPEA and STAART Networks to apply structural brain imaging to the study of autism. The goal of this project is to determine whether investigators can pool existing data from various sites to provide reliable, valid findings that address questions about the brain structures that are affected across the life span in autism.

With the expiration of the STAART and CPEA Networks, NIH plans to create a new, unified centers program in order to maximize coordination and cohesion of NIH-sponsored efforts, to avoid duplication, to allow the most efficient use of resources, and to involve a larger number of investigators. In May 2005, the NIH announced the intention to issue a request for applications (RFA) early in 2006 to solicit proposals for Autism Centers of Excellence (ACE) with an application deadline projected for summer, 2006. NIH encourages investigators of current CPEA and STAART centers, as well as others who believe that they have sufficient expertise and resources to coordinate and implement a center or multi-site research program, to consider

applying for this initiative. NIH plans to commit funds at least at the current funding level for the STAART and CPEA centers. The NIH Guide Notice for the ACE program can be found at <http://grants1.nih.gov/grants/guide/notice-files/NOT-OD-05-048.html>.

c. Facilitation of Research

NIH facilitates research on autism spectrum disorders through a number of mechanisms, including soliciting research applications [i.e., RFAs and program announcements (PAs)], sponsoring meetings and workshops, funding investigator-initiated studies, and supporting research infrastructure. Examples of these efforts are described below.

Five NIH Institutes (NIMH, NINDS, NIDCD, NICHD, NIEHS), the National Alliance for Autism Research (NAAR), Cure Autism Now (CAN), and the Southwest Autism Research and Resource Center (SARRC) sponsored an RFA entitled "RFA MH-05-007: Identifying Autism Susceptibility Genes." The Canadian Institutes of Health Research and the Irish Health Research Board also were involved in the writing of this RFA. The goal of this effort was to solicit large-scale molecular genetic research projects to identify specific genes and gene variants in localized chromosomal regions that produce susceptibility to autism. Five grants (representing three projects) were awarded to researchers at the State University of New Jersey, Robert Wood Johnson Medical School, University of Iowa, Cold Spring Harbor Laboratory, and Emory University. The voluntary organizations and the NIH Institutes established a pool of funds that were used to make 5-year awards that totaled \$10.8 million. These exciting projects represent the current state of the art in human genetics tools and technologies for dissecting the genetic basis of common human diseases. The projects are expected to result in the identification of specific genetic variants that contribute to autism susceptibility. The NIH Guide Notice for this RFA can be found at <http://grants1.nih.gov/grants/guide/rfa-files/RFA-MH-05-007.html>.

Fragile X syndrome (FXS) is the most common cause of genetically-inherited mental impairment, ranging from subtle learning disabilities to severe cognitive or intellectual challenges, such as autism. Approximately 15-25 percent of children with FXS also have autism, and about 2.5-6 percent of children with autistic features have FXS. Therefore, understanding the molecular basis of FXS offers exciting new insights into the etiology and pathophysiology of autism. NIMH, NINDS, and NICHD have entered into a public-private partnership with the Canadian Institutes of Health Research, the Irish Health Research Board, CAN, NAAR, Autism Speaks and the Fragile X Research Foundation (FRAXA) to jointly sponsor a PA entitled "PA-05-108: Shared Neurobiology of Fragile X and Autism." The goal of this PA is to characterize, understand and treat etiological and pathophysiological mechanisms common to both FXS and autism. Applications in response to this PA may be submitted to NIH three times per year over the next 3 years. The NIH Guide Notice for this PA can be found at <http://grants.nih.gov/grants/guide/pa-files/PA-05-108.html>.

NIMH issued PA-05-106, "Deep Sequencing and Haplotype Profiling of Mental Disorders." The goal of this PA is to solicit applications that implement large-scale studies and innovative analytical designs to identify and characterize the different gene variants that influence risk for a given mental disorder. These research developments, whether fundamentally new or evolutionary, may lead to paradigm shifts in the field. Applications written in response to this

PA may propose new technologies for cost-effective, whole-genome analysis and in-depth sequencing of candidate genes in families with autism or in samples of unrelated individuals with autism (and other mental disorders). Results from research funded under this initiative will have direct implications for diagnosis, treatment, and ultimately, prevention of autism and other mental disorders. The NIH Guide Notice for this PA can be found at <http://grants.nih.gov/grants/guide/pa-files/PA-05-106.html>.

NIMH and CAN sponsored a workshop in order to develop a collaborative network on autism consisting of Latin American mental health clinicians and NIH-supported geneticists and neuroscientists in the United States. The workshop was held at the University of Zulia in Maracaibo, Venezuela, and included Latin American researchers from Costa Rica, Brazil, Guatemala, Peru, Venezuela, Argentina, and Mexico, as well as NIH-funded clinical researchers and geneticists. The ultimate goal of the network will be to foster the large-scale data collection from families throughout Latin America for the genetic analysis of autism. Another major focus of this workshop was to promote the incorporation of functional Magnetic Resonance Imaging (fMRI) data into genetic analysis procedures.

NIEHS provided support for a symposium entitled “Environmental Factors in Neurodevelopmental Disorders,” held August 25-26, 2005, in Bethesda, Maryland. This symposium, organized by The Coalition for Safe Minds and the National Autism Association, was intended to unite key researchers in environmental health sciences and neuroscience to create an agenda for future research on the pathogenesis, treatment and cure of neurodevelopmental disorders. Although autism spectrum disorders were the chief focus of this symposium, the broad objective was to define a research roadmap to elucidate the mechanisms by which toxicants may induce neural damage in the developing brain.

In September 2005, NIEHS sponsored a scientific session and workshop at the International Society of Neurotoxicology meeting in Research Triangle Park, North Carolina. The scientific session highlighted emerging findings concerning immune regulation/dysregulation in neurodevelopmental disorders and was intended to stimulate interest among neurotoxicologists in this research area. The associated workshop brought together experts in the fields of neurodevelopmental disorders, neurotoxicology, neurobiology, and neuroimmunology to discuss how environmental agents may disrupt brain development through the induction or exacerbation of immune system dysfunction. The assembled group focused on the potential implications of environmentally-mediated immune dysfunction for autism and other neurodevelopmental disorders. The group developed recommendations for advancing research in this field, and these recommendations will be used for planning future activities.

A large autism genetics project at Johns Hopkins University was funded by NIMH earlier in 2005. This effort employs state-of-the-art technology to study how genetic variation among individuals could influence the risk of developing autism. This study has already yielded interesting results that point to regions on chromosomes 7, 10, and 19 as potential areas of genetic variation in children with autism.

Few training interventions have been tested with fathers of autistic children. NINR-supported investigators have demonstrated that fathers can use child training skills to increase child social

interactive behaviors and vocalizations—two behavioral deficits in children with autism. In turn, it was also demonstrated that fathers can effectively train mothers to use these same skills. Current funding will support (a) the evaluation of this in-home training intervention on parental stress and family cohesion and (b) the development of a Web-based version of this parent training intervention.

NINDS is supporting a 5-year, \$13 million epidemiological study of a large Norwegian birth cohort to explore how various genetic and environmental factors contribute to the development of autism and other neurodevelopmental disorders. This project will evaluate 75,000 women and their infants who are enrolled in the Norwegian Mother and Child Cohort Study (also known as MOBA). The prospective study is examining the effects of infection history, very low birth weight, dietary and environmental exposure to methyl mercury, and vaccination history, among other facts.

NINDS continues to support promising research in the genetics of autism, including support for the development and expansion of resources for research. NINDS currently funds an infrastructure development grant that enables research groups located in the United States, Canada, Europe, and Israel to collaborate on gene discovery for autism. This Autism Genetic Cooperative (AGC) has created a common genetic database, which will enable all AGC participants to pool data from their individual sample collections for more powerful analyses. The AGC also has launched a new Web-based network to help its participants function as a virtual laboratory. AGC members convene an annual workshop at Callaway Gardens in Georgia to discuss new ideas and present various joint studies that have been carried out during the year. At the March 2004 meeting, the AGC decided to expand beyond its six original research groups to include all major groups that have collected samples from families with more than one autistic child.

NIH Institutes have continued to support brain tissue bank collections and tissue distribution resources at several sites. New molecular methodologies to study postmortem brain tissue provide researchers with a unique, high-resolution window into the inner workings of the brain. Only with access to brain tissue can researchers uncover the underlying neuropathology of autism. Activities in 2005 continued to focus on a combined effort by NIMH, NINDS and NIDCD to supplement the Harvard Brain Tissue Resource Center (whose principal funding comes from NINDS and NIMH) for the creation and maintenance of a National Autism Brain Bank. In addition to other federally funded efforts, this national resource will help collect, store, and disseminate postmortem human brain specimens for the study of autism.

The NIH/ACC is working with the NIH Center for Information Technology (CIT) to create and implement a National Database for Autism Research (NDAR). The NDAR is needed in order to achieve several of the goals of the 2004 IACC research matrix, such as “establish resources for genotype/phenotype studies (i.e., bioinformatics, genetic repository).” This database will allow researchers to share the raw materials of research and to make disparate databases available through a single source. NDAR will also assist scientists to reach consensus on common measures, data elements, and methodologies to enhance the comparison of data among various research centers.

NDAR will be used to facilitate data sharing in the Autism Centers of Excellence and will coordinate data with other Federal databases, such as the NIMH Autism Genetics Repository. To better serve the needs of researchers and to foster academic collaborations, NDAR will facilitate public-private partnerships, such as treatment studies conducted with privately funded networks, access to private registries, and other repositories for biological samples. NDAR will enhance communication between researchers and the public and will ensure the rapid dissemination of research findings into clinical practice.

d. Public Input

Parents and guardians of individuals with autism have played a central role in the activities of the IACC and the NIH/ACC. As required by P.L. 106-310, parents are represented on the IACC and have collaborated on numerous NIH activities.

NIH maintains a close collaborative relationship with the autism advocacy community through numerous mechanisms. Advocacy groups representing parents and patients have co-funded research projects solicited through RFAs and have co-sponsored numerous meetings and workshops. In general, NIH is committed to sharing information about NIH processes and research progress with the public, and in turn, is committed to incorporating public views into NIH activities, programs, and decision-making. NIH offers many opportunities for public participation, such as participation in the NIH Director's Council of Public Representatives (COPR), individual Institute advisory council meetings, and specially conducted public forums around the country. In addition, some Institutes, such as NIMH, involve public participants in the grant review process. The autism advocacy community has often been represented in these many venues.

Section 102—Developmental Disabilities Surveillance and Research Programs

a. National Autism and Pervasive Developmental Disabilities Surveillance Program

In 1998, CDC initiated the National Autism and Pervasive Developmental Disabilities Surveillance Program, one of the few programs in the world that conducts active, ongoing monitoring of the prevalence of ASDs in children. Data from the first year of monitoring were published in 2003, providing one of the most complete and comprehensive assessments of autism prevalence in a large U.S. metropolitan area (Atlanta, Georgia). The rate of autism found in this study (3.4 cases per 1,000 children) is higher than the rates found from studies conducted in the United States during the 1980s and early 1990s but is consistent with rates reported in more recent studies (mostly from Europe and Asia).

Since FY 2000, Congress has provided funding to enhance CDC's network of State-based autism surveillance programs. While some programs are more mature than others, 12 States are conducting surveillance in their regions: Alabama, Arizona, Arkansas, Florida, Georgia (CDC's model program in Atlanta), Illinois, Missouri, New Jersey, South Carolina, Utah, West Virginia, and Wisconsin. The monitoring activities of the States are based on the methodology used by CDC's autism and developmental disabilities program in Atlanta. By using similar methods in

multiple sites over time, these projects will provide invaluable data needed to understand the national burden of autism, including trends over time and whether rates of ASDs vary by geographic region, race, or other characteristics. Initial data findings from several States, as well as a second-year data set from CDC's Atlanta program, are being finalized for publication.

The Memorandum of Understanding (MOU) that allowed the Atlanta program to access school records expired in December 2005. However, CDC and the Georgia Department of Education have entered into exploratory conversations to discuss other possible collection methods, with the hope of allowing the Atlanta program to continue.

b. Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology

In September 2001, CDC funded four Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) to conduct collaborative studies on the number, incidence, and causes of autism spectrum disorder and related developmental disabilities. In September 2002, CDC funded a fifth center. The five centers and their surveillance regions are: (1) Johns Hopkins University, which is identifying cases of autism in northeastern Maryland and the entire State of Delaware; (2) the University of Pennsylvania, which covers the Philadelphia metropolitan area; (3) the Colorado Department of Public Health, which concentrates on identifying cases in the Denver area; (4) the California Department of Health Services, which is ascertaining cases of autism statewide, with more intensive monitoring in the San Francisco Bay area; and (5) the University of North Carolina, which covers the Raleigh and Chapel Hill areas.

Using FY 2005 Congressional appropriations for autism, CDC made additional investments in its autism extramural research infrastructure, which when complete, will be able to undertake the largest surveillance and epidemiology study of autism ever conducted. This study will provide important information on potential causes of autism and its impact on families and communities. These investments have allowed CDC to further develop the infrastructure needed for the large-scale collaborative study that the network is uniquely positioned to carry out. In the interim, the sites are continuing to participate in population-based surveillance studies of autism and are conducting special, individual studies on potential causes of autism.

Pilot projects have been published or are under way on a diverse range of topics relating to autism, including potential causes or associations, screening and intervention techniques, impairments, and many others. For example, given the accumulating evidence of the benefits of early intervention, the University of Pennsylvania center is conducting a pilot study of screening toddlers 18 to 24 months of age in general pediatric clinics. The center is training nurses, physicians, educators, and other providers of health and educational services to screen children for signs of developmental disabilities and ASDs.

c. Clearinghouse

As part of the Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology, CDC established a clearinghouse for the collection and storage of data and information in order to facilitate the establishment and operation of surveillance projects and epidemiological studies of autism and related pervasive developmental disabilities. Through the

clearinghouse, CDC makes available any materials or information developed by the CDC-funded centers and States that may be useful for the CDC-funded researchers. Examples of material include publications of epidemiological studies; data management manuals; training materials; research protocols, including questionnaires and other instruments; information on privacy and confidentiality of data; community outreach strategies; and educational materials for professionals, families, schools, and the general public. In addition, the State surveillance programs have an Education and Outreach Committee, which has continued its efforts to increase awareness of autism in each State by assessing information needs. These programs work toward goals of increasing knowledge and awareness among service providers, parents, and the general public. In addition to the larger group, each site also conducts local outreach activities. For example, the Education and Outreach Committee for the surveillance program based out of the Medical University of South Carolina has given more than 25 presentations to local audiences, has had multiple meetings with local stakeholders, and is holding an autism conference for the region.

In September 2002, CDC launched a Web-based Autism Information Center. The information center focuses on the activities of Federal and federally funded programs and the resources offered by these programs. The center includes information for the general public, families, and professionals. Current topics include general information about autism spectrum disorders; activities at CDC and other Federal agencies; State activities funded by CDC; education and services resources for families; resources for researchers; and activities to help children use the Internet to learn more about ASDs. The information center can be accessed from <http://www.cdc.gov/autism>.

In 2001, CDC completed and reported the results of a community-based prevalence study designed in response to parental concern regarding a possibly elevated number of children with ASDs in Brick Township, New Jersey. The study found 6.7 cases of ASD per 1,000 children in the community, a rate similar to autism prevalence estimates from small investigations previously conducted in the United States and abroad. However, this was a small study conducted in just one community, making it difficult to generalize these findings to the larger population, further underscoring the need for dependable, large population-based autism prevalence data. In addition to providing information needed to answer questions about trends in autism, CDC's program and the seventeen States that CDC supports to conduct autism monitoring in their regions will provide the vital background data necessary to evaluate other potential autism clusters.

Section 103—Information and Education

Under Title 1 of the Public Health Service (PHS) Act, Section 103 authorizes the Secretary to establish and implement a program to provide information and education on autism to health professionals and the general public, including information and education on advances in the diagnosis and treatment of autism and training and continuing education through programs for scientists, physicians, and other health professionals who provide care for patients with autism. Funds may be used to provide stipends for health professionals who are enrolled in training programs under this section.

In FY2005, HRSA's Bureau of Health Professions supported the Quentin N. Burdick Program for Rural Interdisciplinary Training to enhance the interdisciplinary education and training of health professionals in rural communities and to address rural health care workforce problems. Projects under the Burdick Program have supported the interdisciplinary education and training of health professionals to address a variety of health care problems, including behavioral/mental health and developmental disabilities in children and adults. The Burdick Program funded the West Virginia University Center for Excellence in Disabilities, which addressed the interdisciplinary education and training of health professionals in developmental disabilities, including autism. The purpose of this project was to improve access to person-centered, quality home health care through the development of clinically competent health care professionals skilled in the interdisciplinary process, and to support a diverse and culturally competent health professions workforce. The program provided interdisciplinary pre-service training for a person-centered approach to home assessments for individuals with disabilities, including those with developmental disabilities and autism, chronic conditions, and the elderly. The Quentin N. Burdick Program for Rural Interdisciplinary Training ended in 2006.

HRSA's Maternal and Child Health Bureau (MCHB) has two long-standing programs that are relevant to the training of health professionals to serve persons with autism and other developmental disabilities. MCHB's Leadership Education in Neurodevelopmental Disabilities (LEND) Program funds 35 LEND programs across the United States to train individuals from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of clinical competence to improve the health of children who have, or are at risk of developing, neurodevelopmental or other related disabilities such as autism and mental retardation. Interdisciplinary faculty and trainees include audiologists, dentists, health administrators, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special education professionals, and speech language pathologists. The Developmental-Behavioral Pediatrics Program funds nine programs, located in institutions of higher learning, to enhance the behavioral, psychosocial, and developmental aspects of general pediatric care. The programs support fellows in behavioral pediatrics to help prepare them for leadership roles as teachers, researchers, and clinicians.

In 2005, the MCHB's Division of Services for Children with Special Health Care Needs continued to support the development of comprehensive, coordinated, community-based service systems for children with autism and their families. The Division provides grant support to the University of Wisconsin-Madison, which serves as a local and national service model for coordination of care through a primary care, medical home to help to promote early

identification and intervention for children and youth with ASD, in addition to coordination of other community-based services that support persons with ASD. In other efforts, the Division used recommendations from the IACC Service Subcommittee's ASD Services Roadmap to begin the development of ASD Service Guidelines to assist healthcare providers with service coordination across the agencies that provide services to children with autism and their families.

CDC has also launched a new activity in awareness and education. In FY 2003, CDC laid the groundwork for an autism awareness campaign, *Learn the Signs. Act Early*. The focus of the campaign is to encourage early screening and detection of autism and other developmental disabilities in order to help children develop and reach their full potential. Congressional appropriations in FY 2004 for autism included approximately \$2.2 million to support autism awareness activities. These funds are being used to launch the campaign and to produce and disseminate materials to parents and providers stressing the importance of early screening and intervention for children with disabilities, especially autism. In addition to continuing to support the existing core components, FY 2005 funding is supporting outreach to another important audience—the child care and early education community, which spends considerable time with young children and is in an excellent position to notice the first indications of potential problems.

Section 104—Interagency Autism Coordinating Committee

a. Establishment

Section 104 mandated the establishment of an interagency autism coordinating committee to coordinate research and other efforts with regard to autism within HHS. Secretary Tommy Thompson delegated the authority to establish the IACC to NIH in April 2001. NIMH at the NIH has been designated the lead for this activity. The Committee has held seven semi-annual meetings.

b. Membership

The Committee's primary mission is to facilitate the effective and efficient exchange of information on autism activities among the member agencies and to coordinate autism-related activities.

P.L. 106-310 specifies that the Secretary may appoint parents or legal guardians of individuals with autism or other pervasive developmental disorders to the Committee. Such appointments are necessary and vital to the conduct of the Committee's mission. In particular, public members of the IACC bring to HHS the concerns and interests of members of the autism community. The IACC serves as a forum, helping to increase public understanding of the member agencies' activities, programs, policies, and research. The Secretary has appointed four public members.

Government agencies represented in the IACC include the following: NIH/ACC members (NIMH, NICHD, NIDCD, NIEHS, and NINDS), HRSA, CDC (specifically, the Agency for Toxic Substances and Disease Registry and the National Center on Birth Defects and

Developmental Disabilities), the Substance Abuse and Mental Health Services Administration, the Administration for Children and Families (specifically, the Administration on Developmental Disabilities), the Food and Drug Administration (specifically, the Center for Biologics Evaluation and Research), the Centers for Medicare and Medicaid Services, the Agency for Healthcare Research and Quality, and the Department of Education (specifically, the Office of Special Education and Rehabilitative Services). A summary of each meeting is posted when available on the NIMH Web site (see <http://www.nimh.nih.gov/autismiacc/index.cfm>).

c. Activities

The IACC has established subcommittees on autism screening and the organization of autism services. Both subcommittees are now working to coordinate activities among IACC members and with the relevant stakeholders in the medical and services communities.

IACC Autism Research Matrix

The House and Senate conferees considering the FY 2003 appropriations for the Departments of Labor, Health and Human Services and Education, Conference Report 108-10, requested that the IACC “convene a panel of outstanding scientists to assess the field of autism research, and to identify roadblocks that may be hindering progress in understanding its causes and best treatment options.” In response to this request, the IACC convened a panel of science experts to document the roadblocks to understanding causes and best treatment options for autism, as well as goals and activities to overcome these roadblocks. A list of roadblocks was created, and the autism research matrix was designed to include goals and activities for the next 10 years. Goals and activities that comprise the autism research matrix generally fall within the following categories: characterization of autism (i.e., phenotype), screening, early intervention, school and community interventions, specific treatments, neuroscience, and epidemiology. After the science panel suggested items for the matrix in July 2003, the membership of the IACC approved the final version of the matrix on November 21, 2003. The Congressional Appropriations Committee Report on the State of Autism Research, summarizing the autism research matrix and plans for implementation, was submitted in April 2004 and may be found at <http://www.nimh.nih.gov/autismiacc/CongApprCommRep.pdf>. The plan for implementing the matrix included the April 2004 reissue of the PA “Research on Autism and Autism Spectrum Disorders” and the funding of projects that will advance individual matrix items. In addition, NIH sponsored a meeting in May 2004 to specifically address the need to improve outcome measures for treatment studies. Furthermore, plans are under way for the National Database to Support Autism Research (described under “Facilitation of Research”), which will contribute to achieving the goals of the matrix.

Autism Spectrum Disorders Services Roadmap

The services subcommittee of the IACC developed a “services roadmap” for ASD. The ASD Services Roadmap is intended to provide a national blueprint to enhance existing systems; expand services for children, youth, and adults with ASD and their families; and coordinate services across systems. The Roadmap was developed within the context of the President’s New Freedom Initiative (NFI) and was based on Executive Order No. 13217, “Community-Based

Alternatives for Individuals with Disabilities.” The Order calls upon the Federal Government to assist States and local jurisdictions to implement swiftly the decision of the U.S. Supreme Court in *Olmstead v. L.C.*, which states that “the United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of the United States.” Thus national impetus exists, through NFI, to reduce barriers to community services and independent living for all individuals with disabilities, including those with ASD.

In the summer of 2004, the services subcommittee of the IACC established a panel of experts to review the state of the field and to provide recommendations for expanding and improving ASD services. This diverse group, called the Expert Working Group (EWG), consists of members with special ASD expertise—service providers, physicians, educators, community program coordinators, researchers, individuals with ASD, and family members of individuals with ASD. Representatives of the EWG presented a status report to the IACC at the November 19, 2004, IACC meeting, which can be found at <http://www.nimh.nih.gov/autismiacc/asdroadmap.pdf>. Members of the services subcommittee have presented progress toward the implementation of these recommendations at each subsequent IACC meeting.

Section 105—Report to Congress

Section 105 requires the Secretary of HHS to submit an annual report to Congress "concerning the implementation of this title and the amendments made by this title." This sixth annual report reflects HHS activities through October 2005.